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Original Research Article

One Previous Owner: Psychological Considerations for Heart Transplant Patients

Feryad. A. Hussain (DClinPsych)*
Clinical Health Psychology Service, North East London Foundation Trust, UK

***Corresponding Author**
Feryad. A. Hussain (DClinPsych)

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Abstract: ***Background:*** Little is known about the psychological challenges facing patients' post-heart transplant surgery. Whilst the research indicates an increase in mental health problems, we have no real information on the role of related contributing psychological factors. ***Objective:*** This paper aims to build upon our understanding of existing research and highlight themes facing this patient group to raise awareness in health teams and to support a more tailored psychological intervention. ***Method:*** It uses conductive research to analyse available research and additionally presents thematic clinical observations, reflecting additional experiences noted by the author during her own therapeutic practice with transplant patients. ***Results:*** The findings reflect a dual illness trajectory with psychological concerns existing alongside and beyond the physical recovery period. ***Conclusions:*** Recommendations are made to support healthcare colleagues to facilitate the care offered to this group of patients using the information presented. What is already known about this topic: Little is known about this topic beyond prevalence studies and a few studies establishing generic links between mental health, quality of life and transplant recovery**.** What does this article add: The paper moves the existing research forward by giving more specific information on potential issues for these patients as a sub section of adjustment research above - building on the broader categories already in place. The information can be used at an individual clinical level but also to introduce to the wider system when offering treatment to this group of patients with the relevant model suggested.

Keywords: Psychological concern post heart transplant surgery/ Psychological factors facing heart transplant patients/ Psychological considerations post heart transplant surgery.

INTRO

"When a man's an empty kettle
He should be on his mettle
And yet I'm torn apart
Just because I'm presumin'
That I could be kind of human
If I only had a heart."
-If I only had a heart: The Wizard of Oz

The absence of a thing allows us to realise its impact on our lives and so its value. For transplant patients, the heart equal life and life equals being alive and as the song suggests it is our hearts that makes us human. As such any impact on this heart, be it emotional or physical has a profound effect on the people we become. There is arguably no greater impact than heart transplant surgery. However, beyond the medical mastery of this quite incredible procedure there is little research on the psychological experiences of patients following transplant surgery. Available information gives us an insight into broader psychological factors but little in the details that may moderate these factors.

This paper aims to build present relevant literature and offer additional psychological themes in the form of dilemmas /challenges facing patients post heart-transplant surgery as manifest in therapy sessions. The information presented is intended to support related healthcare teams in the context of future psychologically informed interventions

Number of transplant patients

Data published by Stewart (2020) reported that whilst the UK has a low rate of heart transplants compared to other European Union nations (2.8 transplants per million people in 2019), the majority of transplants in the UK are carried out in England. Between 2018/19, a total of 173 heart transplants were carried out in the UK with 148 procedures carried out in England alone. At the end of the period 2019/20, there were still 335 patients on UK waiting list: of which 281were in England.

Mental health problems related to post heart transplant surgery

The role of psycho-social factors is not bypassed when considering heart transplant surgery. Indeed, any factors reducing the ultimate effectiveness of this procedure must be prioritised and in cases where patients have significant psychosocial problems, they may either be denied for transplantation or deferred from listing until psychosocial issues are addressed (Scheenkloth, 2019). However, psycho-social factors are not given the same attention post-transplant where often the patient and their families are left to deal with any psychological fallout once safely taken through surgery. The recovery may even be seen to be one of physical re-growth alone with little consideration given to the psychological adjustment and acceptance. As such, psychological therapy with post-transplant patients, presents us with information that helps present a more complete picture of the experience of transplant patients and goes some way to bridge the gap between physical recovery and psychological health.

The rarity of the transplant procedure means that the body of research is rarer still with only a handful of studies and in spite of (historical) acknowledgment of the importance of psychological factors facing transplant patients, post-surgery, there is little contemporary research available (Beidel,1987; Shapiro and Kornsfield, 1989; Rauche and Kneen,1989; Littlefield *et al.*,1996). Relevant research centres on the relationship between the effects of issues, such as psychiatric diagnoses, quality of life (QoL), adjustment issues and more *individual* psychological management strategies such as faith -all offering a valuable insight in to the experience of these patients (Tackman *et al.*, 2000).

Another early study, Dew *et al.* (1999) explored the link between psychiatric disorders, poor/ failure to adjustment on medical compliance post heart transplant surgery and morbidity. Their participants (n=145) received detailed compliance and mental health assessments during the first-year post-transplant and followed up at 3 years. Their results indicated numerous links; a) risk of acute graft rejection was 4.17 times greater among recipients who were not compliant with medications; b) risk of incident CAD was elevated by persistent depression, persistent anger-hostility, medication noncompliance and obesity c) most significantly the risk of *mortality was increased if recipients met criteria for Post-Traumatic Stress Disorder related to the transplant*. They concluded that more attention be given to psychosocial influences and their impact on treatment compliance post-surgery and ultimately, physical health outcomes.

A study by Karapolat (2000) established a link between depression, QoL and functionality in transplant patients. Their patients (n=34) were assessed using Beck Depression Inventory (BDI), the State- Trait Anxiety Inventory (STAI), the Short Form 36 (SF36) and peak oxygen consumption (pVO_2) as outcome measures. They found that post-transplant, there was a significant negative correlation between the BDI and most of subgroups on the SF36. There were significant negative correlations found between the pVO_2 and both the BDI and STAI-trait anxiety score. Statistically significant improvements were noted in all subgroups on the SF36 and all BDI scores after the transplant, *in comparison to the pre-transplant period*. The study demonstrated how functional capacity affected the depression and anxiety in this group. They advised participation in a cardiac rehabilitation programme at an early-stage post-surgery.

In further exploring the link, Milaniak *et al.* (2011) found specifically that *a sense of coherence and coping strategies* were in fact significant predictors for QoL and a diagnosis of depression in this patient group. Specifically, they found that recipients using emotion-focused strategies showed a poorer quality of life, were less satisfied with their health, and displayed a prevalence of depression. They concluded that an assessment of coping strategies and sense of coherence should be made with teams offering skills training in this domain.

Similarly, Doerling *et al.* (2018) studied the link between QoL and mental health as related to *perceived control in management* of their illness trajectory. In their study, (n –113) they concluded that perceived control is associated with improved depressive and anxiety symptoms and HRQOL after transplant. The relationship between perceived control and HRQOL was found to be mediated by depressive and anxiety symptoms. Doerling *et al.* (2018) advised that related interventions should target perceived control to improve overall HRQOL in this group.

Sirri *et al.* (2020) identified the omission of the role of health anxiety in adjustment post-heart transplant comparing health anxiety between patients and a sample of matched controls from the general population. They found that, compared to controls, post-transplant patients had an index of clinically significant health anxiety. Sirri et al (2020) advised cardiologists' and nurses' specific communication skills and psychological treatment strategies may be necessary.

Relatedly, an early study by Harris *et al.* (1995) explored the positive impact of faith on transplant recovery. The study was helpful in raising awareness of the impact of intra-personal factors on recovery. Indeed, Harris *et al.* (1995) recommended the development of specific nursing, social-service, or pastoral-involvement strategies, continuing staff education about the role of religion in patient care.

A related study by Evangelista *et al*. (2005) explored the more practical link *between time and treatment status on changes* in Quality of life. They explored the experience of three groups: transplant recipients (n = 17), transplant candidates (n = 13), and medically stable patients considered too well to receive a transplant (n = 47). Using the Health Related Quality of Life (HRQOL) , Short Form-12 (SF-12) and the Beck Depression Inventory (BDI) at 2 time points during their illness trajectory (baseline and 2 year follow up) . They found that demographic and HRQOL scores were not significantly different among the 3 groups at baseline. During follow-up, physical health and depression scores significantly improved over time in all patients, but *changes in mental health were minimal*. Group comparisons showed that although all patients continued to have low HRQOL scores at the time of follow-up evaluation, medically stable patients had higher mental health scores and less depressive symptoms than their counterparts. Their results certainly support the role and treatment of psychological distress throughout the illness trajectory has an impact on quality of life for these patients and requires specific intervention.

In sum, the studies suggest there is a ‘cycle of recovery;’ Recovery is affected by QoL, further affected by mental health which is influenced by levels of adjustment which are moderated by more specific psychological cognitions which relate to individual management strategies including cognition regarding mastery control as well as the impact of individual differences such as strength of spiritual beliefs. Recommendations consistently suggest greater exploration and management of psychological aspects of recovery by nursing and medical staff as well as specialist psychological services. The existing research offers us a picture of the core issues that influence and moderate that chain of events. This being the case, a greater understanding of psychological cognitions would be of significant advantage to healthcare professionals, in supporting transplant patients to build a stronger foundation on which to build their recovery.

Challenges facing patients post-heart transplant surgery

In building on the above, we may look for the relevant information most directly in therapy sessions with post-transplant patients.

The following are over-arching themes and dilemmas that capture the common challenges facing post-transplant patients. They, in part, support existing research and in part introduce new issues existing at a more personal/ subjective level. These intra-personal issues are often obstacles to healthy adjustment and can be further complicated by inter-personal expectations of not only friends and family but also healthcare professionals who understandably view the surgery from the sole position of a life being saved. Whilst no one is more grateful to be alive than the patient themselves, they are the only ones who can truly understand the complexity of surviving that experience.

The following dilemmas are of course transitory in nature but can be seen as part of an emotional trajectory and may be seen as a linear or circular process with patients moving between stages. Similarly, the related time frame will vary and be moderated by pre-existing issues around health, co-morbid mental health problems, self-identity and individual differences.

Congenital Vs acquired cardiomyopathy

The experience of a cardiomyopathy related transplant patient returning to life with some memory of a once functioning heart is markedly different from those patients born with congenital heart problems and who have never known a healthy. The ‘new-new-heart’ adjustment here is not held in the old memories of the patient – rather it is about making a new memory and the experience of being able to trust their new heart to work with an awareness that the patient has no idea what a ‘normal’ heart feels and sounds like. As such, the ‘congenitally ill’ transplant patients may be more sensitive to the sounds of the heartbeat, envision the internal flow and be uncertain as to what is normal and so experience increased panic at the slightest changes causing considerable confusion and concern. For those with an acquired cardiomyopathy, there will be some memory of a once healthy heart and the adjustment to a ‘new-old- heart’ will centre more closely around return to what was a normal heart. In both the over- attentive response to the new heart will be part of the adjustment but the levels of related trust and uncertainty of the transplanted heart may vary according to the source problem.

Death circumstances of the donor: Gratitude and guilt

The circumstances of the death of the donor are seemingly clear – with donors generally coming in through accident or injury. However, this is not the complete list of donors and on occasions donors may be the victims of more disturbing circumstances such as murder or suicide. Whilst health teams take precautions, to protect both the patients and the donor's family regarding disclosure of the donor's nature of death; each comes with its own consequences. This may result in a form of 'survivors' guilt, expectations of use and value, an inability to detach oneself from an unspoken obligation to the donor; all of which can impact on the relationship with the new heart. For example, where the donor is in an RTA there will be the predicted guilt of gaining from the death of someone who was not expected to die but a sense of the heart wanting to live and a motivation to survive. However, in the case of a suicide, the emotions are much more complex where the patient is surviving on a heart that belonged to someone who no longer wanted that heart to beat. Symbolically for the patient, this can be, less a case of the body rejecting the heart more the heart rejecting the life. This can result in a very confusing sense of 'guilty gratitude.' As above, the guilty gratitude may apply to both, but the level complexity involved in managing this varies according to nature of death.

Ownership or a loan

The transplant experience makes the acceptance of an 'alien body' into to one's own a stark reality. Adjustment in this context is closely tied into the language of transplants such as donor, recipient, accepting/ rejecting the new hearts etc. Though necessary these are all a constant reminder that the organ once belonged to someone else which can often lead to the patient feeling conflicted about who actually owns the heart. The fact that it resided in another body before the present one can leave the patient feeling that this heart is 'on loan' which in turn impacts on their sense of ownership of the heart. This can further result in the patient feeling uncertain about psychologically accepting the new heart causing a further emotional split around surviving because of a heart that is not their own, resulting in poor integration and adjustment to the new heart. It is experienced as freedom from death with ties.

Old self and new self: Am I still me?

A new heart will understandably leave some patients experiencing 'identity confusion,' moderated by perceptions of the personality characteristics of the donor and the perceived, expected use (by the patients and their family as well as the donor) of the new heart. Stories of personality changes post- transplant have a deep impact on patients vulnerable/emotional states and imagination often feeds into a sense of disturbance relating to 'incomprehensible' phenomenon. With little attention being paid to the more 'spiritual' changes patients can often feels fearful of the new heart itself and a sense of unpredictability which may result in hyper-sensitivity to slight changes in personality which are then not attributed to the process of transplant and related psychological adjustment but attributed to more paranormal explanations. This can result in cognitive dissonance with their own known sense of self and perceptions of the hearts previous owner again causing disruption to adjustment.

Old lifestyle or new lifestyle

The transplant of a new heart can often leave patients reviewing their pre-existing health behaviours. These changes and motivations may be moderated by a sense of obligation to the donor who 'died' to keep them alive and so a pressure to change one's behaviour as a reaction to a misplaced sense of guilt as opposed to a response of informed decision making about one's future health management. This it has implications for adjustment due to the potential impact on one's wider social circle which is often cemented by food, drink and exercise rituals.

Myself or my family

The impact on families is significant at an individual as well as systemic level. The event exists in pre-existing *as well as* emerging family dynamics, as such patients can feel caught between their own and familial / friends' expectations and reactions. This can often delay adjustment as patients prioritise the emotional needs of others before their own – if only to make their own recovery easier. The reliance by healthcare services on families to support transplant patients, post-recovery often appears to exclude any support for them from services often leaving the patient to manage the adjustment for and of the family as well as themselves.

The above themes are not by any means a complete list but the themes all impact on patient adjustment in a more practical way and offer healthcare professionals an insight in to the patients position and their on-going journey.

Considerations for use

The issues mentioned above are most likely to be raised once physical health is stabilised and medical teams gradually reduce patient contact allowing the patient space and time to process the experience in a safe space. However, there is currently no research to suggest there is a predicted process or pattern following surgery, it is important to consider how these concerns may be highlighted and by whom.

By whom?

As mentioned earlier, whilst these issues may be raised and explored in therapy with a qualified psychologist, it is of equal importance that all professionals within transplant healthcare teams are aware of the potential concerns of their patients, particularly individual consultants and nursing staff who may have long-standing relationships with patients, post-surgery for on-going medical reviews etc.

The information presented gives healthcare teams the relevant tools to increase their understanding of this group, allowing them to understand the underlying reasons for potential problems with adjustment which may feed in to a wider problem with recovery. The rarity of the heart transplant often creates a sense of loneliness and fears of being misunderstood and patients can feel pressured in to silence. In being familiar with the issues, healthcare teams are able to validate, normalise and contain the distress of their patients and support adjustment post-surgery in a more comprehensive manner.

NB: This is not to suggest healthcare teams explore these issues for patients who require specialist input, but they may be used a guide for potential future psychological support.

How?

The implementation of the knowledge may be done by employing the pre-existing Level 2 cancer support 3S's model. Developed by the London Cancer Network, the model has been adapted in various settings and is delivered by psychologists working with healthcare staff.

The 3S's (Stuck/ Suffering/ Safe) is a framework for professionals to apply the idea of 'adjustment.' When a professional is concerned about a patient, they are encouraged to consider the whether the patient is Stuck (or deteriorating), how they are Suffering and whether Safety is an issue. Using regular supervision sessions, the psychologist is able to support staff to support their patients manage common concerns post-transplant.

This form of psychological supervision may be adapted within services to accommodate this patient group using existing research to develop a post – heart transplant specific model.

CONCLUSION

Heart transplant patients and healthcare teams are in a unique situation. The challenges of physical recovery are well established but psychological consequences require a greater understanding. A greater understanding of the specific issues facing these patients can be used through employing an adapted Level 2 psychological supervision model, to offer heart transplant patients the most relevant support and enable them to live their best lives.

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